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ABSTRACT

This executive summary reviews activities over the past 5 years of the Kansas Early Childhood Research Institute (KECRI). The Institute has addressed transition issues faced by infants and young children (and their families) who have a disability or are at risk for developmental delay. KECRI goals are stated and the importance and impact of the Institute's research program are summarized. Principles of the KECRI Model of Transitions are noted. During this period KECRI conducted 11 research projects and an overarching continuing longitudinal study, trained 63 graduate students, disseminated findings at over 300 professional meetings and 200 pre-and inservice training sessions, and published almost 200 papers and chapters. Seven major research projects are summarized: (1) "Planning the Transition from the NICU (Neonatal Intensive Care Unit) to the Home" (Nancy E. Meck); (2) "Transitioning Preschool Children with Severe and Profound Multiple Disabilities from a Special Education Classroom Program into Mainstream Montessori Preschool and Child Care Programs (Barbara Thompson and Jane Wegner); (3) "Verbal Interactive Skills Training for Transitions" (Mavel L. Rice and Kim A. Wilcox); (4) "Programming Successful Classroom Transitions: Assessment of Children's Survival Skills and Classroom Requirements" (Judith J. Carta et al.); (5) "Promoting Successful Transition to the Primary Grades: Prediction of Reading Problems in Speech and Language Impaired Children" (Hugh W. Catts); (6) "Role of Professionals in Successful Transitions" (Winnie Dunn); and (7) "The Longitudinal Study of Families and Children in Transition" (Marion O'Brien et al.). (Contains 22 references.) (DB)



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Kansas Early Childhood Research Institute on Transitions

University of Kansas

Executive Summary

December 1993

Co-Principal Investigators:

Mabel L. Rice, Ph.D. Marion O'Brien, Ph.D.

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KANSAS EARLY CHILDHOOD RESEARCH INSTITUTE

EXECUTIVE SUMMARY

December 1993

INTRODUCTION AND OVERVIEW

The Kansas Early Childhood Research Institute (KECRI) has addressed transition issues faced by children across the 0-8 age span who have a disability or are at risk for developmental delay, faced by their families, and faced by the agencies that provide services to children with disabilities in the early childhood period. The KECRI research has been based upon the recognition that transition periods, while associated with growth and opportunity, also often require disruptive and stressful accommodations by all the individuals involved.

To the young child with a disability, from whom accommodation and adaptation are constantly required, the addition of new demands placed by a new environment may be overwhelming. To the child's family, as well, transitions add to already difficult day-to-day problems. Changes in services and/or personnel associated with transitions, along with new demands made by changes in routines that affect the entire family, may reduce the parent's ability to cope, create resistance to planning, promote defensive behavior, and result in serious misunderstandings between parents and service providers as well as disruption in the child's educational program. The transition needs of these children and families are often overlooked by professionals providing medical, social, or educational services to children and families. Transitions resulting from changes in the placement of children, changes in the nature or form of needed services, or changes in personnel within existing service agencies place added burdens on already overworked staff. Further, the extensive need for communication during periods of transition requires time, patience, and resources that may be in short supply.

During the past five years, KECRI has brought together researchers from a variety of disciplines to focus on the needs and concerns of young children with disabilities and their families during transitions from one set of services to another. The set of research projects conducted by KECRI has addressed the full range of issues surrounding the transitions from hospital to home and community services, from preschool into kindergarten and the primary grades, and from segregated to integrated services. While the main focus of KECRI has been the experiences of children and families, component studies have also examined issues facing service providers who implement transitions. In addition, a longitudinal study is under way to track the service histories and transition-related concerns of a group of 100 children with identified disabilities or at high risk for developmental delay. Taken together, these projects have enhanced our knowledge of issues important to successful transitions across the early childhood period.

Each of the KECRI component projects has also developed and disseminated products describing successful transition practices and procedures, and has trained students and service providers in effective strategies for transition. Thus, the KECRI work will be continued through



implementation of the transition interventions developed in these projects in a wide range of programs and disciplines.

GOALS OF THE KECRI

- 1. Develop and evaluate solutions to problems created by the transitions faced by young children with disabilities and their families.
 - 1-1. DEVELOP AND EVALUATE INTERVENTION STRATEGIES TO HELP HIGH-RISK INFANTS AND PARENTS PLAN FOR AND SUCCESSFULLY MANAGE TRANSITION FROM HOSPITAL TO HOME AND INTO INFANT SERVICES.
 - 1-2. DEVELOP AND EVALUATE INTERVENTION STRATEGIES TO HELP PRESCHOOL CHILDREN WITH DISABILITIES AND THEIR FAMILIES PLAN FOR AND SUCCESSFULLY MANAGE TRANSITION FROM HOME TO PRESCHOOL AND BETWEEN CLASSROOMS, INCLUDING THE TRANSITION FROM SPECIALIZED TO INTEGRATED SERVICES.
 - 1-3. DEVELOP AND EVALUATE INTERVENTION STRATEGIES TO HELP KINDERGARTEN AND PRIMARY CHILDREN WITH DISABILITIES AND THEIR FAMILIES PLAN FOR AND SUCCESSFULLY MANAGE TRANSITION INTO THE PUBLIC SCHOOLS AND BETWEEN PUBLIC SCHOOL CLASSROOMS.
- 2. Develop and evaluate procedures and practices to help service providers from a variety of programs and disciplines provide needed transition planning and implementation services to young children with disabilities and their families.
 - 2-1. IDENTIFY SPECIFIC TRANSITION INTERVENTION NEEDS AND THE APPROPRIATE TIMING OF INTERVENTION SERVICES.
 - 2-2. DEVELOP METHODS TO ASSESS SKILLS REQUIRED BY PARTICULAR ENVIRONMENTS AND ENVIRONMENTAL ACCOMMODATIONS TO PROMOTE SUCCESSFUL TRANSITION OF CHILDREN WITH DISABILITIES INTO THOSE ENVIRONMENTS.
 - 2-3. DEVELOP STRATEGIES FOR PROMOTING INTERAGENCY COOPERATION AND COMMUNICATION AS WELL AS PROCEDURES FOR EVALUATING THE SUCCESS OF TRANSITION PRACTICES.
 - 2-4. Develop strategies for involving families in transition planning and including transition intervention objectives into individualized family service plans.
- 3. Train graduate students and professionals across a variety of disciplines in procedures and practices that promote successful transition of young children with disabilities from one set of services to another.
- 4. Disseminate training materials, curriculum procedures, transition intervention practices, family involvement procedures, and transition information to service providers, families, and university training programs.



IMPORTANCE AND IMPACT

The KECRI's research program responded to the following priority and emphasis areas identified in the original call for proposals for an Early Childhood Institute focused on Transitions:

CHILD-FOCUSED

► Procedures have been developed and evaluated to facilitate transitions during the early childhood period, birth to eight years of age;

SERVICES/ PERSONNEL

▶ Procedures have been developed to facilitate transitions that occur when there are changes in services and in personnel who coordinate and provide services;

BETWEEN SETTINGS

▶ Procedures have been developed to address transitions that occur between hospital and home, home and infant services, infant services and preschool services, preschool services and primary school, primary school grades, and nonintegrated-integrated programs;

PSYCHO-SOCIAL CHILD & FAMILY

▶ Procedures have been developed that are individualized to meet the psychological and emotional needs as well as the service needs of the child and family;

CHILD COMPETENCIES & SETTING ACCOMMODATIONS

 Procedures have been designed to help children develop the knowledge, skills, and competencies needed in new settings as well as to describe the accommodations in both current and future environments that promote successful transitions;

AGE AT INTERVENTION

▶ Procedures have been developed that identify when implementation is most effective and with whom implementation is most effective;

IFSP STRATEGIES

 Procedures have been developed that serve as models and strategies for including transitional intervention objectives in individualized family service plans and individualized education programs;

METHODS & MATERIALS

▶ Procedures are accompanied by methods and materials that service providers can use to monitor outcomes of interventions.

OVERVIEW OF THE INSTITUTE

The KECRI work addressed the full scope of the goals. Eleven individual research projects were carried out; in addition, a longitudinal study is continuing and provides descriptive data on services provided to and transition experiences of families of children with disabilities or at high risk of developmental delay, from birth into school. Training and dissemination activities have been integral components of the research projects and central to the work of the Institute.



The collective contribution of the Institute is the identification and development of procedures to facilitate transitions during the early childhood period, from birth to age eight, across different service settings, disabilities and risk conditions, and family circumstances. The KECRI work extends the previously available information about transitions in several ways. Among the accomplishments of KECRI are development of transition planners for infants and their families (Project 1.2); a more complete description of survival skills needed for preschool and kindergarten settings (Projects 3.1, 2.3, 2.2), and documentation at the infancy level of parents' and health care providers' perceptions of transition needs (Projects 1.2 and 1.3).

Through the KECRI work, the dimensions of child competencies that impact on transitions, such as verbal interaction and linguistic/phonological abilities, multiple and profound disabilities, and social abilities have been explored (Projects 2.3, 3.2, 2.2, 2.4). Consideration of these particular child competencies is essential in the design of individualized transition strategies. Several of the KECRI projects have evaluated the use of videotapes as a way of providing transition intervention with parents of children who have disabilities or are at risk (Projects 1.1, 1.3). Other projects have explored intervention procedures that require accommodation by service providers and service settings, in contrast to strategies that place much of the accommodation burden on children or their parents (Projects 2.3, 2.2, 3.2, 4.2). Thus, the set of studies included in the KECRI has addressed all the dimensions included in transitions.

The KECRI Model of Transitions

The KECRI work has integrated transition issues from the perspectives of children, families, and service providers. In order to do so, a theoretical framework was needed that allowed for an operational definition of transition and its outcomes, and the ways in which children, families, and professionals interact. Following Bronfenbrenner (1986) and Gallimore, Weisner, Kaufman, and Bernheimer (1989), Rice and O'Brien (1990) described a transition model in which a child is viewed as a member of a family that is in turn part of a broader social and cultural community. In this model, families are not passive in the face of outside social and economic forces, but are instead agents of change, capable of acting to modify or counteract outside influences.

Transitions are one source of influence on families of children with special needs. Their success in promoting child progress depends on a number of factors both within and outside the family. The conceptual framework underlying the KECRI approach to transitions includes the following:

- 1. EVERY TRANSITION OR CHANGE IN SERVICE PROVIDERS HAS MULTIPLE INFLUENCES ON A FAMILY, E.G., CHANGES IN EXPECTATIONS FOR THE CHILD'S BEHAVIOR, IN THE FAMILY'S FINANCES, IN TRANSPORTATION NEEDS, AND IN THE CHILD'S OPPORTUNITIES TO PLAY WITH NEIGHBORHOOD CHILDREN.
- 2. TRANSITIONS ARE DIFFICULT MAINLY BECAUSE THEY REQUIRE ACCOMMODATIONS IN DAILY ROUTINES FOR ALL INVOLVED: CHILD, FAMILY, AND SERVICE PROVIDERS MUST MAKE ADJUSTMENTS INVOLVING NEW SETTINGS, PEOPLE, BEHAVIORAL EXPECTATIONS, AND VARIATIONS IN THE DAILY "BUSINESS" OF LIVING.
- 3. THE IMPACT OF A TRANSITION ON EACH PERSON MAY BE EVALUATED BY THE NUMBER OF ACCOMMODATIONS REQUIRED. THE FEWER THE CHANGES IN THE INDIVIDUAL'S BEHAVIOR OR ROUTINE, THE EASIER THE TRANSITION WILL BE FOR HIM OR HER.



- 4. One measure of the success of a transition intervention is the extent to which it encourages accommodations that are sustainable over time. For most families, transition interventions should minimize the impact on existing family routines, or make those routines easier.
- 5. ACCOMMODATIONS REQUIRED BY TRANSITIONS ARE NOT NECESSARILY NEGATIVE. WHEN A CHILD MOVES TO A MORE APPROPRIATE SETTING, FOR EXAMPLE, THE CHILD'S PROGRESS AND HAPPINESS WILL TYPICALLY CONTRIBUTE POSITIVELY TO THE FAMILY'S PERCEPTION OF THE SUCCESS OF THE TRANSITION.
- 6. Interventions to promote positive and reduce negative effects of transitions may involve both distal aspects (e.g., financial policy) and proximal aspects (e.g., information about how to care for a baby going home from the NICU). And prediction of transition impact must be made in terms of both individual factors and interactive combinations of factors.
- 7. AGENCIES AND INDIVIDUALS WHO PROVIDE SERVICES TO CHILDREN AND FAMILIES ARE ALSO AFFECTED IN MULTIPLE WAYS BY TRANSITIONS. THE NATURE, TIMING, AND QUALITY OF THEIR EFFORTS TO FACILITATE TRANSITIONS ARE INFLUENCED BY THE EXTENT OF ACCOMMODATIONS REQUIRED ON THEIR PART AS WELL AS THEIR PERCEPTIONS OF THE STRENGTHS AND NEEDS OF CHILDREN AND FAMILIES.
- 8. THE DEVELOPMENTAL STATUS OF THE CHILD AFFECTS THE EASE OR DIFFICULTY OF A TRANSITION, PARTICULARLY WITH REGARD TO THE AMOUNT OF INVOLVEMENT REQUIRE. BY THE FAMILY AND THE ABILITY OF THE CHILD TO UNDERSTAND AND HELP PLAN FOR CHANGE.
- 9. WHETHER A TRANSITION IS NORMATIVE OR NON-NORMATIVE (BRONFENBRENNER, 1986) INFLUENCES PARENTS' AND SERVICE PROVIDERS' PERCEPTIONS OF THE TRANSITION. NORMATIVE TRANSITIONS ARE EXPECTED (E.G., TAKING A NEW BABY HOME FROM HOSPITAL AFTER BIRTH, ENTRANCE TO SCHOOL, MARRIAGE). NON-NORMATIVE TRANSITIONS ARE UNEXPECTED (E.G., BIRTH OF A BABY WITH A DISABILITY, IDENTIFICATION OF A DISABILITY IN THE PRESCHOOL YEARS, A SUDDEN SHIFT IN SERVICE SETTINGS). SUCH TRANSITIONS ARE ALWAYS STRESSFUL BECAUSE THERE IS LITTLE OR NO OPPORTUNITY TO PREPARE FOR THEM. NORMATIVE TRANSITIONS ARE NOT WITHOUT STRESS, EITHER. SINCE NORMATIVE TRANSITIONS ARE SOCIALLY EXPECTED, PARENTS AND SERVICE PROVIDERS OFTEN FAIL TO ANTICIPATE THE NEED FOR ACCOMMODATIONS BY THE CHILD, THE FAMILY, OR THE SERVICE SETTING. THUS, ALL TRANSITIONS, WHETHER EXPECTED OR SUDDEN, REQUIRE PLANNING IF THEY ARE TO BE COMPLETED SUCCESSFULLY.

This framework has been applied across the full scope of the KECRI projects and the birth-to-eight age range, covering transitions from hospital to home, infant services to preschool, preschool to primary school, and nonintegrated to integrated programs, from varying service settings and professional disciplines, and for a variety of disabilities. The research methodology has varied as a function of the particular questions of study, and the resulting transition interventions varied according to the children's age, the targeted goals, and the service settings.

It has become clear that there are multiple interactions among variables that affect transitions. In particular, the personal characteristics of a family member such as a child with special needs influence the processes by which the environment affects families (Bronfenbrenner, 1986). The KECRI work has been directed to identification of transition processes appropriate for intervention with particular children, that can be carried out by families and service providers.

The results of the KECRI components are summarized below. As a collective enterprise, the KECRI conducted 11 research projects and an overarching longitudinal study, trained 63 graduate students, disseminated findings at over 300 professional meetings and almost 200 pre- and inservice training sessions, produced a Newsletter, and published almost 200 papers



and chapters. This summary describes each of the seven research projects that continued through the five years of the Institute. (Projects 1.1 [Evans], 2.1 [Fowler & Cooper], 2.4 [Etzel & LeBlanc], and 4.1 [Fawcett & Suarez] were completed in previous years and final reports for those projects were already submitted.) A preliminary report is provided for Project 5.0, the longitudinal study of Families and Children in Transition (FACT), which is still in progress.

INSTITUTE RESEARCH PROJECTS

INFANT STUDIES

The first set of research projects addressed infants' transition from the Neonatal Intensive Care Unit (NICU) to home. For many children with disabilities, the transition from NICU to home is one of the first of a series of major transitions that will be experienced, and may be difficult for families for a variety of reasons. The emphasis in these projects was the development of tools that NICU staff could use to help families through this transition.

PROJECT 1.2. PLANNING THE TRANSITION FROM THE NICU TO THE HOME

PRINCIPAL INVESTIGATOR, NANCY E. MECK, Ph.D. CHILD DEVELOPMENT UNIT, UNIVERSITY OF KANSAS MEDICAL CENTER

The goal of this project was to facilitate the move from NICU to home for high-risk infants and their families by improving the transition planning strategies used by families and professionals. Although the importance of good transition planning has long been recognized by NICU social workers and nurses, their current transition-planning procedures do not consistently incorporate all aspects of Part H of P.L.99-457 or the eight principles of family centered care.

Three studies were conducted to accomplish the following objectives:

- 1.2-1 To develop and administer a retrospective transition interview to obtain information about the transition from NICU to home from the family's point of view.
- 1.2-2 To develop a transition planner needs assessment to identify family and infant needs and help communicate those needs to health care professionals.
- 1.2-3 To evaluate the effectiveness of the transition planner needs assessment in facilitating the transition from the NICU to home.
- 1.2-4 TO DEVELOP A PROCEDURAL MANUAL ON THE USE OF THE TRANSITION PLANNER NEEDS ASSESSMENT FOR NICU PROFESSIONALS WHO WISH TO INCORPORATE SUCH A FORM INTO THEIR DISCHARGE PLANNING PROCESS.

The first study was designed to identify what families were experiencing during their child's hospitalization, how important each of these factors was, the parents' level of satisfaction with the information received, and what families are experiencing post-discharge in terms of support and services accessed.



Based on the data collected in the first study, a transition planner needs assessment was developed. The second study was designed to evaluate the use of the transition planner needs assessment compared to routine discharge planning.

The third study was designed to field-test the revised transition planner, renamed the NICU Individualized Transition Planner.

Significant Findings and Products

Three instruments, a manual and brochure were developed as a result of this project:

The <u>Retrospective Interview</u>, a 23-page interview conducted with parents, can be used as a needs assessment or as an evaluation instrument. Prior to intervention, it can be used to assess the need for additional staff training in the NICU. Alternatively, it may be used to evaluate an intervention.

The NICU Individualized Transition Planner, designed as a precursor to an Individualized Family Service Plan (IFSP), incorporates the components of P.L. 99-457, Part H; embraces the eight components of family-centered care; and enables parents, health care professionals, educators, and early intervention specialists to identify the strengths and needs of families making the transition from the NICU to home. The NICU Individualized Transition Planner is a tool that can be used by parents and professionals to identify a family's strengths and needs as they work through the transition process from the NICU to home. It can be used as a checklist, a record of information discussed, and as a process. The way in which it is used and completed should be determined and approved by the family.

The third instrument is the <u>Transition Evaluation</u> form. This interactive interview addressed the eight components of family-centered care, the principles outlined in P.L. 99-457, Part H, elements of consumer satisfaction.

To accompany the use of the NICU Transition Planner is A manual for using the NICU Individualized Transition Planner: A structured process to facilitate the transition from NICU to home. This manual is designed to help families and professionals understand the origin and philosophy behind the NICU Individualized Transition Planner, the many versatile ways in which it can be useful, and when and where ideally it would be used. Sample case vignettes have been included to help illustrate the diversity of family characteristics and conditions under which the NICU Individualized Transition Planner might be applied. Where appropriate, the reflections of parents who used the NICU Individualized Transition Planner when their infant was hospitalized are included.

The results of this project have been presented at 16 professional meetings and 18 training workshops/seminars. Presentations have included local and regional meetings with physicians and other health care providers and state agencies, and national meetings of early childhood professionals. Project findings will also be disseminated through written materials to be targeted toward interdisciplinary journals in fields such as education and child development.



PROJECT 1.3. IN-HOME INTERVENTION TO FACILITATE THE TRANSITION FROM NICU TO HOME

PRINCIPAL INVESTIGATORS:

KATHLEEN McCluskey-Fawcett, Ph.D.

DEPARTMENT OF PSYCHOLOGY

MARION O'BRIEN, Ph.D.,

DEPARTMENT OF HUMAN DEVELOPMENT

The substantial differences between the NICU and home environments can have significant impact on the parent and child when the infant is moved from the hospital to the home setting. Many parents are not adequately prepared to assist their infant in making the adjustment from the NICU to the home.

In order to promote optimal transition from NICU to home, and to ameliorate some of the effects of prolonged hospitalization, it is crucial that parents/caregivers be given the knowledge and skills necessary to adapt their own behavior to meet the challenges of their child, and to help their child accommodate to the new environment. A smooth transition at this crucial juncture should facilitate parent-infant interaction (Eckerman & Oehler, 1992) and the subsequent attachment process (Klaus & Kennell, 1982) and increase the infant's developmental potential.

In this project, videotaped intervention strategies were developed and evaluated specifically to acquaint parents with their infant's experience in the NICU, the effects this environment can have on the infant, and what types of parenting strategies can be used to help the infant make a rapid, healthy transition to the home environment.

Very few studies have been attempted in the area of NICU to home transitions. In the past, such programs have been appropriate primarily for families that have ready access to ongoing services and support. Unfortunately, in many areas, families are geographically or economically isolated from such services. The purpose of this project was to develop and field test informational videotapes that would facilitate the transition to home for infants with prolonged neonatal hospitalization.

The objectives of this project were:

- 1.3-1 TO IDENTIFY THE PROBLEMS/STRESSES EXPERIENCED BY THE CHILD AND FAMILY, ASSOCIATED WITH THE TRANSITION FROM NICU TO HOME FROM THE POINT OF VIEW OF PARENTS AND PROFESSIONALS.
- 1.3-2 TO PRODUCE INSTRUCTIONAL VIDEOTAPES ABOUT PREMATURE INFANT CARE, THE NICU, AND THE HOSPITAL-TO-HOME TRANSITION.
- 1.3-3 TO EVALUATE THE EFFECTIVENESS OF INSTRUCTIONAL VIDEOTAPES 'N PROMOTING A SMOOTH TRANSITION FROM THE NICU TO HOME.
- 1.3-4 TO PREPARE AND EVALUATE A PROCEDURAL MANUAL ON THE PRODUCTION OF INSTRUCTIONAL VIDEOTAPES FOR NICU MEDICAL PROFESSIONALS WHO WISH TO MAKE VIDEOTAPES OF THEIR HOSPITAL NURSERY.
- 1.3-5 TO INVESTIGATE FAMILY ADJUSTMENT DURING THE HOSPITAL-TO-HOME TRANSITION FOLLOWING THE BIRTH OF A PRETERM INFANT AND RELATE THESE FINDINGS TO RESEARCH ON PARENTAL ADJUSTMENT AND CARETAKING RISK IN FAMILIFS WITH PREMATURE INFANTS.



Several studies were conducted to meet these objectives. First, two studies were done to determine the needs of parents and professionals in the transition process. The results of both of these investigations guided the content of the videotapes that were then developed.

Significant Findings and Products

The first study (McCluskey-Fawcett, O'Brien, Robinson, & Asay, 1992), conducting in-depth retrospective interviews with mothers of premature infants, revealed high levels of stress at several points in the transition process from NICU to home. The findings make it clear that interventions for families of premature infants have not kept pace with medical interventions for the infants themselves. Such programs should: (a) provide parents with the information and skills they need to feel competent and empowered as parents while their infants are hospitalized, and (b) address the emotional needs of families of medically at-risk infants. Seeking information is a useful coping strategy for many parents, and NICU staff should encourage and enhance parents' opportunities to learn about the NICU and become directly involved in infant care.

Overall, the long-term well-being of premature infants can be enhanced by the provision of family-centered intervention that recognizes the needs of parents to be directly involved in infant care as soon and as often as possible during the infant's hospitalization. Parents need to practice caregiving skills and learn to interpret their baby's needs and signals so they can provide appropriate and sensitive caregiving after their baby comes home.

The second study (Sheikh, O'Brien, & McCluskey-Fawcett, 1993) solicited professionals' reports of what parents learned during discharge teaching and parents' reports of what they remember being taught. Conducted in conjunction with Project 1.2, this study indicated large discrepancies between the reports of hospital staff and parents. Staff and parents agreed on the nature of the information that is important for parents, but disagreed substantially on what specific information was actually provided. Many of the discrepancies were in areas critical to the care of preterm infants such as signs of illness, feeding, and growth and development. Parents did not remember information presented to them, or material was presented in such a way that parents did not learn it. Clearly, an alternative method of discharge teaching is needed to insure that all parents receive the information they need to provide optimal care for their premature infants.

Based on the findings of these two studies, two instructional videotapes were produced and evaluated for their effectiveness as part of a discharge teaching process. The first tape, Introduction to the NICU, was designed to give parents a video-guided tour of the NICU, introduce technology and medical terminology, describe the people on the medical staff, and generally make parents feel welcome in the NICU environment. The second tape, Caring for Your NICU Baby, describes how parents can interact with their baby in the hospital and at home and models specific caregiving practices for premature infants. Both tapes are intended for parents of all education levels, and were designed to be inexpensive so parents could take them home and view them at their convenience. A pamphlet to accompany the tapes was also developed to reinforce the information on the tapes. A series of evaluation studies was conducted with parents and professionals to assess the effectiveness of the tapes. Results of these studies indicated that both tapes are effective in communicating information about prematurity and practices in the NICU, and that parents found the tapes useful, their anxiety



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decreased, and their satisfaction with the NICU increased. Professionals who viewed the videos found them to be excellent and indicated a high level of satisfaction with the content and potential usefulness of the tapes.

The instructional videotapes designed to enhance discharge teaching are the primary product of this project and have been shown to be very effective means of intervention with families of preterm infants. Additionally, this project has produced six papers in refereed publications and two chapters for professional audiences, has disseminated the findings at 20 professional meetings nationwide, and has conducted seven inservice/preservice training presentations.

PRESCHOOL STUDIES

The second set of research projects focused on transitions in the preschool years. Two projects continued through the Institute's five years, both addressing transitions for preschoolers from somewhat specialized classrooms into inclusive education settings. The preschool populations and transition issues differ across these two projects, one studying children with severe and profound multiple disabilities, and the second, children with speech/language disabilities alone.

PROJECT 2.2. TRANSITIONING PRESCHOOL CHILDREN WITH SEVERE AND PROFOUND MULTIPLE DISABILITIES FROM A SPECIAL EDUCATION CLASSROOM PROGRAM INTO MAINSTREAM MONTESSORI PRESCHOOL AND CHILD CARE PROGRAMS

PRINCIPAL INVESTIGATORS:

BARBARA THOMPSON, Ph.D.
DEPARTMENT OF SPECIAL EDUCATION

JANE WEGNER, Ph.D.
DEPARTMENT OF SPEECH-LANGUAGE-HEARING

The overall goal of this project was to identify and investigate critical factors in the effective transition of preschool children with severe and multiple disabilities from special education classrooms into inclusive community preschool/child care programs. Children who attended segregated special classrooms for half-days were transitioned into inclusive classrooms, at first for the remaining half-days, and finally full-time. The original receiving environment was a Montessori program, but during replication studies the project expanded to other early childhood programs. A key feature of the transitions was the use of a paraprofessional trained as inclusion facilitator to accompany and support the child with special needs in the inclusive setting.

The specific objectives of the project were as follows:

- 2 2-1 TO DETERMINE ATTITUDES, CONCERNS, AND PERCEPTIONS OF THE CHILDREN, FAMILIES, AND PROFESSIONALS DURING TRANSITION.
- 2.2-2 TO DETERMINE THE CONTENT AND FORM OF PREPARATION AND ONGOING SUPPORT NEEDED FOR TRANSITION SUCCESS.
- 2.2-3 TO DETERMINE THE DEGREE OF INTEGRATION WITHIN THE CLASSROOM THROUGH DESCRIPTIONS OF THE INTERACTIONS THAT OCCUR.



Over a series of studies, procedures were developed and documented that result in: (a) identification of content and procedures for preparing staff to conduct a full inclusion model of early childhood education for preschoolers with severe disabilities, (b) sustained positive reciprocal social interactions between children with severe disabilities and children typical in development; and (c) effective incorporation of best practice instruction and meeting individual child needs within the mainstream program. Study I was an ethnographic study portraying the events, issues, and meanings of the children's transition from the viewpoints of key participants in the original site and identifying both key strategies that affected development of the integration model and transitional markers of program evolution. Studies II-VI were a series of observational and single-subject studies of the nature of the children's interactions and the variables that support positive interactions and child accommodations. Studies II and III described and compared the communication profiles of five children based on an analysis of transcriptions of classroom interactions as the children participated in a segregated special education preschool (which they attended half-days) and a mainstream Montessori preschool (which they entered for the remaining half-days). Study IV involved a series of reliability analyses and validation of the CEVIT (Coding Environmental Variable and Interactions on <u>Tape</u>), an observational coding system developed for this project as a means of reliably documenting ongoing classroom activities, environmental variables and interactions variables simultaneously. Study V employed the CEVIT to compare activities, interactions and environmental variables across the same children as Study II in both the segregated special education classroom and the mainstream preschool. Study VI employed the CEVIT to compare child interactions, activities and key environmental variables (such as children's use of adaptive equipment) across inclusion facilitators and time. Studies VII and VIII were replications. Study VII involved a counterbalanced multiple-probe design simultaneously replicated across four facilitators and eight children in a new site and examined the effect of specific facilitation strategies on the participation and interactions of the children. Study VIII used qualitative procedures to examine the perceptions of the participants in replication sites as a means of validating the conclusions of Study I.

Significant Findings and Products

Classrooms that employ a child-initiated approach (such as Montessori) to early education are able to sustain successful placement of young children with severe disabilities. Children with severe disabilities have significantly more peer partners and more communicative interactions in mainstream preschools than in special education preschools. The adults' interactions with the children are markedly different in the two settings: special education staff are more didactic and directing, while in the inclusion settings staff are more facilitative of the child's interaction with themselves, others, and the materials. Further, the children spend longer at one activity in the inclusion setting, where timing is more under their control, than in the special education classroom. Accommodations (such as adaptive equipment for supporting positions, and the availability of materials) are comparable with those in high quality special education classrooms and suggest appropriate and highly engaging environments can be provided in mainstream community programs. The use of special equipment does not appear to negatively affect interactions between children. While children are apt initially to treat a preschooler with severe multiple disabilities as an infant or toddler, this tends to diminish over time when information about the child and his or her disabling condition is offered to the typical peers.



Finally, children with severe disabilities do form special relationships (friendships) with some of their typical peers that appear to be mutually satisfying and maintained over time.

Role confusion and frustration are major factors that may negatively affect satisfaction, especially of the special education teacher and the paraprofessional facilitator for a child with severe disabilities in a mainstream classroom. Direct staff training on facilitative strategies that support child-to-child interactions is necessary to ensure their application in the classroom. Training must be also employed to ensure that these strategies are generalized to other children and maintained over time. Paraprofessionals used to facilitate the inclusion of children with disabilities at times appear to reduce the regular early childhood teacher's interacts with the child. While ongoing classroom support is needed to accommodate children in early childhood classrooms with typical ratios of 2 adults to 20–24 children, more research on teaching staff about their roles and how to "fade" from the child with a disability is needed.

The concerns expressed by parents of children with disabilities and staff prior to transition into inclusive environments are consistent with recent literature. In general, parents of typically developing children support the inclusion of children with severe disabilities when the number of children is limited to reflect natural proportions of the population (1%). Staff and parents tend to become more positive about the effects of inclusion on children with severe disabilities after direct participation in a program. After participating in an inclusive early childhood program, parents prefer placement for inclusive school-age services and this impacts on transition issues from early childhood to school-age services for young children with severe disabilities.

The results of Studies I and II formed the basis for development of three training videotapes, along with accompanying viewers' guides, developed as an adjunct to Project 2.2 with separate funding. The viewers' manuals illustrate key points offered by the videotapes and suggest training content and activities. A Circle of Inclusion explains the rationale for inclusive early childhood education, illustrates the transition of children with severe disabilities into an inclusive setting, and discusses the concerns and experiences of staff and parents. The Process of Communication: Facilitating Interaction with Young Children with Severe Disabilities in Mainstream Early Childhood Programs depicts five strategies for supporting child-child interactions that include young children with severe disabilities. The Process of Instruction: Facilitating the Participation of Young Children with Severe Disabilities in Mainstream Montessori Preschools depicts five overarching strategies that support instructional inclusion of young children with severe disabilities across various early childhood program models.

The project's findings are published in the <u>Handbook for the inclusion of young children with severe disabilities: Strategies for implementing exemplary full inclusion programs</u> (Thompson et al., 1993). The book describes this project's inclusion model and offers strategies for (a) planning and start-up of an inclusive program, (b) preparing staff to function effectively in inclusive programs, (c) accommodating the needs of families and individual children, and (d) facilitation of social interaction and instructional inclusion. It includes checklists and forms developed in the project and a list of additional resources. The book is intended as a practical guide and inservice education resource for community early childhood education/child care personnel and families interested in implementing early childhood programs that fully include



young children with severe disabilities. It can also serve as a textbook for preservice students in Early Childhood and Early Childhood Special Education personnel preparation programs.

Additional dissemination has been accomplished through 20 presentations at professional meetings and 14 inservice training workshops across the country.

The project model for transition into inclusive services for young children with severe disabilities has been formally incorporated into the school district early childhood service delivery system of the two communities in which the original and the replication sites were located. Both districts were awarded three-year funding from the Kansas State Board of Education to assist these LEAs in incorporating the project's early childhood inclusion model and strategies. Additional funding from the Office of Special Education Programs, U.S. Department of Education was awarded for a three year outreach project to implement strategies needed to transition young children with severe disabilities into inclusive kindergartens in Kansas City, KS.

PROJECT 2.3. VERBAL INTERACTIVE SKILLS TRAINING FOR TRANSITIONS

PRINCIPAL INVESTIGATORS:

MABEL L. RICE, PH.D.

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DEPARTMENT OF SPEECH-LANGUAGE-HEARING

DEPARTMENT OF SPEECH-LANGUAGE-HEARING

This project has evaluated the role of appropriate verbal interactive skills in the successful transition of children with speech or language impairments into traditional classrooms and has developed intervention strategies to improve verbal interactive skills. Verbal interaction is a major dimension of adjustment for children with communication deficits transitioning from preschool to kindergarten. As preschoolers, children with communicative disabilities are often reluctant to participate in verbal interactions with their peers, preferring to rely on adults to mediate their interactions (Rice, Sell, & Hadley, 1991). This tendency to avoid initiation of conversation with one's peers becomes a concern as children transition into kindergarten. It was predicted that verbal interactions would be highly sensitive to changes in personnel and to the demands of the kindergarten setting.

The studies in this project involved children served in the Language Acquisition Preschool (LAP) at the University of Kansas. Five main studies were undertaken:

- 1. THE VERBAL INTERACTIVE SKILLS OF TYPICAL CHILDREN AND CHILDREN WITH SPEECH/LANGUAGE IMPAIRMENTS (S/LI) WERE DESCRIBED PRIOR TO, UPON ENTRY TO, AND AT THE END OF THE FIRST YEAR OF KINDERGARTEN. THIS INFORMATION WAS COLLECTED WITH THE SOCIAL INTERACTIVE CODING SYSTEM (SICS) (RICE, SELL, & HADLEY, 1991). THE CROSS-SECTIONAL SAMPLE INCLUDED 26 CHILDREN AND THE LONGITUDINAL SAMPLE INCLUDED 17 CHILDREN.
- 2. THE <u>Speech Language Assessment Scale</u> (Hadley & Rice, 1993) was designed to gather information about parents', teachers', and speech/language pathologists' (SLPs) evaluations of children's verbal interactive "kills, to be used for assessment and intervention planning.
- 3. THE <u>TALKING AT SCHOOL</u> (HADLEY, WILCOX, & RICE, IN REVIEW) QUESTIONNAIRE WAS DESIGNED TO GATHER INFORMATION FROM PRESCHOOL AND KINDERGARTEN TEACHERS REGARDING THEIR ATTITUDES ABOUT CHILDREN'S VERBAL INTERACTIONS IN THE CLASSROOM. WE WERE INTERESTED IN THE EXTENT TO



WHICH TEACHERS ENCOURAGED OR DISCOURAGED TALKING DURING THE VARIOUS ACTIVITIES OF THE SCHOOL DAY.

- 4. THROUGH BI-ANNUAL CONTACT WITH PARENTS, THE TRANSITIONS INTO ELEMENTARY SCHOOL OF CHILDREN WITH S/LI WERE FOLLOWED. SPECIFICALLY, WE TRACKED THE EXTENT TO WHICH CHILDREN RECEIVED SPECIAL EDUCATION SFRVICES AND OTHER SUPPLEMENTARY EDUCATIONAL ASSISTANCE AS WELL AS PARENTS' PERCEPTIONS OF THEIR CHILDREN'S' TRANSITIONS FROM PRESCHOOL TO ELEMENTARY SCHOOL.
- 5. AN INTERVENTION STRATEGY, VERBAL REDIRECTION, WAS EVALUATED AS A MEANS FOR INCREASING CHILDREN'S INITIATIONS TO PEERS. THIS STRATEGY BUILT ON THE INCLINATION OF CHILDREN WITH S/LI TO INITIATE TO ADULTS MORE OFTEN THAN TO PEERS. FOUR CHILDREN AND ONE ADULT WERE INVOLVED IN THE INITIAL STUDY; TWO MORE CHILDREN AND ANOTHER ADULT WERE INVOLVED IN A REPLICATION STUDY.

Significant Findings and Products

The study of children's verbal interactive skills indicated that children with S/LI initiated to peers proportionately less often than their typical peers, and children with S/LI more often initiated to adults than to peers. This means that children with S/LI may have fewer opportunities to engage in social interactions that facilitate language and social development. As a result, teachers and SLPs must plan intervention to facilitate the verbal and social interactions of children.

Data collected with the SLAS indicated that parent and professional ratings of children's speech and language abilities were highly correlated with one another. The SLAS can be a valuable tool in the assessment process and ongoing determination of progress for children with S/LI.

Investigation of teachers' attitudes toward talking indicated that teachers encouraged more talking in child-centered activities than teacher-directed activities. Kindergarten teachers were more restrictive than preschool teachers in the talking allowed during teacher-directed activities. The change in verbal expectations between preschool and kindergarten constitutes a challenge for children with S/LI. Teachers need to be made aware of the different verbal interactive demands presented by specific activities and of their own expectations and rules for interactions. It is then equally important for teachers to explicitly share these rules with the children, highlighting the changes in the rules as they occur throughout the day.

The follow-up data on children's transitions from LAP into the early elementary years indicated that almost two-thirds of the children received academic support or special services, including speech/language therapy, occupational therapy and Chapter One assistance. These findings corroborate earlier reports in the literature that many children with S/LI are likely to need educational support during the school years. Further, they underscore the importance of viewing language impairments not as a transient phenomenon but as a disability with long-term implications for social and academic functioning.

The redirect studies indicated that following a brief period of training (i.e., two hours) teachers were able to redirect children's initiations so as to facilitate initiations to peers. Prior to training, teachers were not likely to use a redirect strategy as a means to facilitate children's



initiations to peers. Peers responded favorably to these initiations, most often providing a conversationally appropriate response. The redirect intervention period was associated with a significant increase in the mean proportion of spontaneous peer initiations. Redirects are a promising strategy for facilitating peer initiations in classroom intervention programs.

The primary products of this research are the three instruments developed and tested by this project for use in assessment and planning speech/language interventions and transition interventions, along with a set of scholarly articles describing the research, findings and recommendations for practice. The Social Interactive Coding System (SICS) (Rice, Sell, & Hadley, 1991) was developed as a tool for describing the verbal interactive skills of both children with speech/language difficulties and children with typical language development in the preschool and early school years. The Speech Language Assessment Scale (SLAS) (Hadley & Rice, 1993) was developed to solicit parents', teachers', and speech/language pathologists' evaluations of children's verbal interactive skills, and is intended to be used for assessment and intervention planning. The questionnaire Talking at School (TAS) (Hadley, Wilcox, & Rice, in review) was designed to gather information from preschool and kindergarten teachers regarding their attitudes about children's verbal interactions in the classroom, in particular, the extent to which teachers encourage or discourage talking during their daily classroom activities.

These three instruments appear in refereed journals. Eight other refereed articles and three chapters present the project's findings directly, while a further 17 refereed articles and nine chapters and books describe related findings and issues. The findings have also been disseminated nationally and internationally in over 80 lectures and conference presentations, and 50 pre- and inservice training workshops or seminars have been conducted across the country.

ELEMENTARY SCHOOL STUDIES

Entry into the early primary grades is the topic of the next set of research projects. Expectations for children's behavior, skills children are assumed to possess already, and skills to be acquired are radically different in elementary school compared to preschool — especially for children coming from special early intervention settings. The transition into the elementary grades brings challenges to all children, but especially to children with disabilities who may be less than fully prepared for the demands and expectations of the public school classroom. Project 3.1 focuses on "classroom survival skills", general knowledge about expected classroom behavior, while Project 3.2 focuses on a particular skill that children will be expected to acquire very early in their academic lives — that of literacy. Acquisition of both kinds of skill is crucial to continued success in school. Early identification of children who may need assistance in acquiring these skills is a necessary aspect of facilitating their transition into school.



PROJECT 3.1. PROGRAMMING SUCCESSFUL CLASSROOM TRANSITIONS: ASSESSMENT OF CHILDREN'S SURVIVAL SKILLS AND CLASSROOM REQUIREMENTS

PRINCIPAL INVESTIGATORS:

JUDITH J. CARTA, PH.D.
JUNIPER GARDENS CHILDREN'S PROJECT

JANE B. ATWATER, Ph.D.
JUNIPER GARDENS CHILDREN'S PROJECT

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JUNIPER GARDENS CHILDREN'S PROJECT

The goal of this project has been to develop, validate, and disseminate a measurement system to assess classroom survival skills in young children with and without disabilities. This assessment instrument has successfully been used to facilitate the assessment and identification of aspects of classroom structure and teacher behavior that influence the children's opportunity to acquire and practice classroom survival skills.

The transition from preschool to elementary school involves a multitude of changes for children (Hains, Fowler, & Chandler, 1988; Vincent, Salisbury, Walter, Brown, Gruenwald, & Powers, 1980). Children are required to learn new routines, meet new teachers and peers, and adjust to new classroom expectations. For many young children with special needs, these changes have been compounded in the past by the drastic differences between the structure of the preschools they attend and mainstream kindergarten classrooms (Carta, Atwater, Schwartz, & Miller, 1990; Carta, Sainato, & Greenwood, 1988; Hains, Fowler, Schwartz, Kottwitz, & Rosenkoetter, 1989). These settings differ in terms of classroom ecology, teacher behavior, and academic expectations. For example, if students have been in special education preschools, they have spent the majority of their time in individual instruction or small group activities, whereas the kindergarten students receive the majority of their instruction in large groups. Children in special education preschool classrooms have typically received a high rate of praise and teacher direction, while children in kindergarten classrooms have been expected to complete tasks independently with minimum teacher direction, feedback, or individual instruction.

While the inclusion movement has shifted the focus somewhat away from the transition from special preschool to mainstream kindergarten to the transition into inclusive environments more generally, the different demands and expectations of the "next educational environment", whatever that may be for a given child, must be considered when early interventionists design instructional programs for special preschools (Anderson-Inman, 1981; Carta, Schwartz, Atwater, & McConnell, 1991). School success, especially in the early elementary years, depends on appropriate classroom behavior as well as academic performance. In order to facilitate success in the educational mainstream for young children with disabilities, preschool programs must prepare students with disabilities to meet the social, cognitive, and behavioral requirements of the kindergarten classroom (Carta et al., 1990; Rule, Fiechtl, & Innocenti, 1990).

Many researchers have documented that classroom expectations and classroom survival skills are important in predicting and evaluating later school success. Therefore, our goal has been to develop a multi-faceted assessment instrument that could be used by teachers and program evaluators to assess students' level of competence in identified classroom survival skills and to compare that level to the classroom expectations in the future environment. The discrepancy between students' present level of competence and their next teachers' expectations has served effectively as a target for interventions in both preschool and regular kindergarten classrooms.



The studies carried out in this project related to the establishment of psychometric properties for the ACCESS instrument. The studies documented the reliability of the instrument, assessing both interobserver agreement and test-retest stability of measurement, and the concurrent and predictive validity of the instrument. Finally, discrepancy analyses documented students' level of survival skill functioning in their preschool setting and the level of functioning of students in classrooms where the target children were expected to be placed the following year.

Significant Findings and Products

The primary product generated by this product was a multi-component assessment system for evaluating young children's transition to new environments. The system, ACCESS, contains components for observing children in their sending and receiving settings, for assessing children's performance relative to teacher's expectations in the next setting, and teacher's ratings of the importance of various areas of expectation. This system was the keystone for a set of survival skills interventions that we validated as part of another OSEP project. The assessment and intervention are now being disseminated nationwide through an EEPCD outreach project. Presently available are the assessments, an intervention manual, and a training videotape.

Several studies were conducted to document the psychometric properties of the ACCESS instrumentation. First, throughout all three years of observation studies, interobserver reliability of the ACCESS observation system remained high. Second, based on our analysis of the stability of ACCESS data across multiple observations, we have concluded that six observations are necessary to account for day-to-day variability in student and teacher behaviors and to adequately sample the range of possible classroom activities. Third, related to predictive validity, we documented that children who received higher Survival Skills Ratings from their preschool teachers were more likely to receive regular education placements for kindergarten entry. Fourth, we examined the discriminative validity of the ACCESS observation system at the preschool level and reported differences in both student and teacher behaviors across: (a) disability levels (mild, moderate, and severe); (b) teachers' Survival Skills Ratings (highest versus lowest rated students in each classroom); and (c) eventual kindergarten placement (regular or special education). We also examined the predictive validity of both the ACCESS observation system and the Survival Skills Rating Form for children as they moved through prescnool, kindergarten, and first grade. To do so, we have examined relationships between pre-post assessments of children (i.e., structured assessments and teacher ratings obtained at the beginning and end of each school year) and children's averages across the school year for behaviors recorded with the ACCESS system. In preschool special education classrooms, statistically significant relationships were found for teachers' prompting during independent task periods. Children who had required more teacher prompting throughout the year received lower scores on the Brigance and lower teacher ratings for independent skills. In kindergarten classrooms, children's behaviors during group instruction (appropriate engagement and compliance with prompts) were positively related to all components of the teachers' post-test Survival Skills Ratings. Also, children who had been most actively engaged during independent periods received the highest teacher ratings for independent skills. Similarly, in first grade, those children who exhibited more appropriate classroom behaviors, and who required less teacher prompting, received higher Survival Skills Ratings and lower behavior problems ratings (Kohn) at the end of the year. Thus, a large number of expected, logically consistent



relationships were found, particularly in the primary grades, lending support to the predictive validity of the ACCESS observatior, system.

Finally, we described a method for comparing the classroom behavior of an individual target child to that of classroom peers. Peers included: (a) other at-risk children (i.e., children with disabilities and children identified as at risk for academic problems) and (b) index children (i.e., children identified as "B" students by their teachers). We examined grade-level differences for groups of both at-risk and index children. For group instruction activities, children's levels of appropriate engagement were similar across grade levels and child groups; but, compared to their index peers, at-risk children were less compliant to teacher prompts. For both independent worktime and transition activities, at-risk children had a decline in active engagement from preschool to first grade, whereas index children maintained relatively stable engagement levels. The most striking difference between the preschool special education classroom and regular primary grade classrooms was in the level of teacher prompting during independent activities, emphasizing the importance of preparing children for the next environment.

The ACCESS instrument is available from the principal investigators. The research and findings of this project have been described in eight refereed journal articles and two chapters. Related reports have appeared in a further 14 journal articles and seven chapters. Additionally, the work of this project has been disseminated at 50 conference presentations and in 15 inservice training meetings nationwide.

PROJECT 3.2. PROMOTING SUCCESSFUL TRANSITION TO THE PRIMARY GRADES: PREDICTION OF READING PROBLEMS IN SPEECH AND LANGUAGE IMPAIRED CHILDREN

Principal Investigator, Hugh W. Catts, Ph.D. Department of Speech-Language-Hearing

Perhaps the most significant of the new challenges accompanying the transition from preschool into the primary grades is the acquisition of literacy. It is during the primary grades that most children acquire the basic skills of reading and writing. Because literacy skills play such an integral role in education, success in acquiring these skills may have a significant impact on children's future academic performance.

For most children, the transition into the primary grades and literacy is fairly smooth and met with success. For 10 to 15% of children, however, this transition is much harder. One group particularly at risk for reading disabilities in this transition are children with speech and language impairments. Numerous investigations have shown that these children often demonstrate reading difficulties upon school entry. Because of their early difficulties in learning to read, children with speech and language impairments often go on to experience significant academic problems.

An important component in intervention for children with speech/language impairments is early identification of reading disabilities. If the children with speech/language impairments who have the greatest risk for reading disabilities could be identified prior to school entry, intervention might be able to limit reading and academic difficulties. This project addressed the issue of early identification of reading disabilities in children with speech and language impairments.



The project sought to identify individual differences among children with speech and language impairments that would be predictive of reading achievement in the primary grades. Previous research with large cross-sections of children suggest that a number of language measures may be related to reading. This work indicates that children's conscious awareness of the speech sounds in words (i.e., phonological awareness) is a prerequisite to learning to decode printed words. Research also suggests that ability to rapidly retrieve verbal information (naming objects or letters) and to hold this information in short-term memory may predict reading achievement in the primary grades. While children with speech and language impairments often receive preschool language assessments, measures of phonological awareness, rapid naming, or verbal short-term memory are seldom administered or considered in relation to reading achievement.

Two studies were carried out. In the first, the relationship between language measures and reading achievement was investigated in children with speech/language impairments. Seventynine kindergartners who had been referred for speech-language evaluations in two public school districts and 32 matched control children with no history of speech/language problems participated. Subjects were administered a test battery that included measures of phonological awareness, rapid naming, and verbal short-term memory. Subjects were followed into first and second grade and were given tests of reading achievement. Results indicated that approximately half of the children with speech/language impairments were demonstrating reading disabilities in first and second grade. Furthermore, measures of phonological awareness and rapid naming administered in kindergarten were found to predict reading achievement in the primary grades. A large percentage of the variability in reading achievement (approximately 40-50%) could be explained by performance on the phonological awareness and rapid naming measures.

On the basis of these results, the second study developed and evaluated a screening instrument, consisting of a revised set of phonological awareness and rapid naming tasks, which was administered to a second cohort of 53 subjects in kindergarten. Subjects' reading achievement was evaluated at the end of first grade. Results showed that the screening measures were closely related to reading achievement. Furthermore, analyses indicated that the screening battery predicted reading levels in first grade (e.g., good or poor readers) with a high 85% accuracy.

Significant Findings and Products

This project demonstrated that kindergarten measures of specific language abilities were good predictors of reading achievement in the primary grades. Several measures were combined to form a screening battery. This battery predicted reading success/failure with a high degree of accuracy. Therefore, this battery has the potential to contribute significantly to programs directed at early identification of reading disabilities in children with speech and language impairments. The screening test, combined with additional measures/information (e.g., family history of reading disabilities, early literacy experience) should be able to identify children at risk for reading disabilities before they enter school and actually experience difficulties.

The results of this project and their implications for educational and clinical practice have been disseminated in various ways. This information has been presented as part of workshops or papers at 6 national and 21 state/regional conferences in 5 countries and 18 states or provinces during the last 3 years. The results of this project have also been published in 3 refereed



journals and 3 book chapters. To date, approximately 60 requests from 13 countries have been made for reprints of these articles.

PARENT AND PROFESSIONAL STUDIES

In these studies, transition issues are examined from the perspective of the professionals and parents who come together as a team to work on a child's Individualized Education Plan (IEPs). To help families and children plan for and accommodate to a transition from one service setting to another, the transition needs to be directly and formally addressed by the team. Project 4.2 has investigated strategies to facilitate transition planning in team meetings.

PROJECT 4.2. ROLE OF PROFESSIONALS IN SUCCESSFUL TRANSITIONS

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Project 4.2 focused on the role of professionals as they interact with families within an interdisciplinary team, and with professionals from other agencies. Specifically, the project examined how interdisciplinary teams plan and implement transitions, particularly in the Individualized Education Planning (IEP) process, and how issues in service provision and interagency communication are dealt with. Several strategies were identified as useful to improve the transition process for future teams, and for preservice interdisciplinary training.

Project 4.2 had three objectives:

- 4.2-1 TO IDENTIFY ROLES OF KEY PROFESSIONALS IN SEGREGATED AND INTEGRATED INFANT, PRESCHOOL, AND PRIMARY SCI'OOL PROGRAMS.
- 4.4-2 TO IDENTIFY THOSE TRANSITION NEEDS OF CHILDREN AND FAMILIES THAT ARE COMPATIBLE WITH PERCEIVED PROFESSIONAL ROLES AND THOSE THAT ARE NOT MET WITH PRESENT PROFESSIONAL ROLES.
- 4.2-3 TO DEVELOP INTERVENTION STRATEGIES THAT ENHANCE PROFESSIONALS' USE OF ALREADY PRESENT TRANSITION SKILLS AND PROMOTE OTHER NEEDED SKILLS NECESSARY FOR SUCCESSFUL TRANSITION.

In-depth analyses of the IEP meeting and document preparation process were conducted as a way to capture the salient features of professionals' contributions to the program and transition planning activities. Discussions at IEP meetings and written goals set on the target children's IEP documents were subjected to analyses including examinations of (a) curricular areas covered in the planning, (b) rapport building among team members, and (c) transition planning.

A second area of investigation revolved around the transition process itself. The researchers explored the parents' and elementary teachers' (the post-transition service providers) perceptions about the transition process, and compared their impressions with actual time spent planning specific transition activities with the family. There was higher satisfaction after the year that there were more discussions and plans made about the transitions.



The researchers also took a preliminary look at parent and professional perceptions about various professional activities completed on behalf of children. Findings indicate that although professionals and families expressed different views, professionals recognized the family's view. There seems to be a movement toward a family-centered perspective of service provision.

Significant Findings and Products

Study 1: The IEP Process

- 1. Among the participants at team meetings, it was parents and preschool teachers who made the most contributions to the IEP meeting process.
- 2. IEP meeting participants made different kinds of contributions, primarily within discipline expertise.
- 3. A primary focus at preschool IEP meetings may be rapport building with the family.
- 4. The oral IEP meeting discussion and written IEP document emphasized different areas, suggesting that these two activities are different processes that serve different purposes.
- 5. Transitions were discussed during IEP meetings, but there were no overt goals written about the transition on the IEP document.

Study 2: The impact of inservice and planning activities on attention given to transition issues

- 1. Inservices to provide teams with feedback about their performance related to transition planning and meetings to create plans increased attention given to transition issues in end-of-year team meetings.
- 2. Teachers at the post-transition sites reported an improvement in their preparation for receiving the target children when there were more transition activities the previous spring.

Study 3: Congruence of family/professional priorities

- 1. Families and professionals did not set the same priorities for work on behalf of children.
- 2. Professionals were able to identify what family priorities are, but did not set the same priorities for themselves.

Study 4: Comparison of meetings with and without parental attendance

- 1. Professionals contributed in a similar manner whether parents were present or not
- 2. More "other" comments (greetings, acknowledgements, and other utterances not addressing curricular or transition issues) were made in meetings attended by parents, suggesting professionals' perceived need to build rapport. These studies indicate that the IEP process



needs to be revisited. Although it is important for multiple disciplines to contribute to a comprehensive picture of a child's needs and strengths, mechanisms to more actively include families in substantive conversation and planning are required. Some of the family-centered strategies implemented in the IFSP process may also serve the IEP process effectively.

Community-based teams profit from inservice and planning time directed at improving their attention to the child's transition issues. This is a cost-effective and functional means of transmitting information to effect change within this large social system, and may be productively applied to other topics as well.

Products

The primary products from this set of studies are professional presentations and journal publications to disseminate the findings. The original plan was to create a package for teams, but each team in the study created a unique plan, suggesting that widely-published articles that describe what happened would be a more appropriate medium for dissemination. The following articles will be disseminated:

Dunn, W. (submitted). <u>Analysis of the preschool Individualized Education Planning Process:</u> <u>Current practices and directions for the future</u>.

Dunn, W. (in preparation). <u>Impact of inservice and planning time on the team's attention to transition issues</u>.

In addition, presentations have been made annually at several national meetings for professionals who work with young children with disabilities and their families. Examples of meetings addressed include those of the American Occupational Therapy Association and The Association for Persons with Severe Disabilities (TASH).

LONGITUDINAL STUDY

Overarching the entire set of Institute research is a continuing longitudinal study of families and their at-risk children from the time of their birth (and initial NICU placement) until they reach kindergarten age. All KECRI investigators contributed to the design and methods of this study, which examines services and transitions in depth for each family.



PROJECT 5.0. THE LONGITUDINAL STUDY OF FAMILIES AND CHILDREN IN TRANSITION (THE FACT STUDY)

PRINCIPAL INVESTIGATORS:

MARION O'BRIEN, PH.D. HUMAN DEVELOPMENT

MABEL RICE, PH.D. SPEECH-LANGUAGE-HEARING JUDITH E. THIELE, PH.D. FORMERLY OF CHILD DEVELOPMENT UNIT

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The overall goal of the study of Families and Children in Transition (FACT) is to document the consequences of real-world transitions by following individual children and their families as they move from service provider to service provider. This study has collected extensive information about families, children's health records and developmental status, and use of services, in order to document the frequency and nature of transitions between service providers in early childhood, identify child and family characteristics that place particular children at risk for difficulties during transition, identify aspects of transitions that lead to problems for families and disruption in services to children, and examine the aspects of transition that promote successful accommodation by children and families and ensure continuity of services.

One hundred and three infants and their families, of a range of demographic and socio-economic backgrounds, were recruited from a neonatal intensive care unit (NICU). Because of their NICU placement, these infants were considered at risk for developmental difficulties. Based on perinatal medical conditions, the infants were categorized as high risk (i.e., identified disability), moderate risk (e.g., very low birthweight, serious illness without known developmental sequelae), or low risk (prematurity, mild illness). The risk groups did not differ demographically.

Families were visited in their homes five times over the children's first three years: shortly after the infant's discharge from the NICU, then at chronological ages 10, 18, 27 and 36 months. Complete data for the three years are available for 87 children (31 high risk, 26 moderate risk and 30 low risk). Of the others, 16 children died, left the study or could not be located, and 7 (high-risk) could not complete developmental testing because of their disabilities.

At each home visit, a battery of family and child measures was administered. Through parent interview, data were collected on family demographics, employment and household, child health history, and services received by child or family. Questionnaires elicited data on parent social support, perceptions of child-rearing difficulties, and perceptions of child behavior problems. The child's developmental status was assessed using the Bayley Scales of Infant Development [Bayley, 1969] at 10 and 18 months, and the Battelle Developmental Inventory Screening Test [Newberg, Stock, Wnek, Guidubaldi, & Svinicki, 1984] at later ages, and language development was assessed at 36 months (Peabody Picture Vocabulary Test - Revised [Dunn & Dunn, 1981]).

Significant Findings and Products

The FACT Study is the first effort to follow a group of children at risk for disability and developmental delay from birth throughout their early childhood years with a focus on service delivery. The product of the study is documentation of the variables that influence service



provision and access to services, of transitions between service providers, and of the perceptions of families about services received. Combined outcome measures of child progress and family functioning allow identification of "best practices" in service delivery, continuity of services, and transition planning.

The main findings so far (tracking the children from birth to 36 months) are as follows.

<u>Child development</u>. A striking finding is that, for all risk groups, there was a dramatic <u>decline</u> in developmental trajectory from infancy to age 3, as well as a time x risk interaction. While the high-risk group had significantly worse developmental test scores than the low-risk group at 10 months, these differences were minimal later. By 27 months, <u>all</u> groups (even the low-risk) were performing below expected levels on standard developmental measures, and by 36 months group means were about 1 SD below the norm. Language development scores at 36 months were similarly low for all risk groups.

Child developmental outcome was not significantly related to any other child or family measure such as parent report of child behavior problems, parenting daily hassles, perceived social support, maternal education or marital status. There was a marginally significant main effect for poverty, but no poverty x risk-group interaction. Thus, family demographics were not strongly associated with the children's developmental status. Although the three risk groups differed significantly in child health history (high-risk children visited the doctor for illness more often and had many more hospitalizations and surgeries than the other two groups), repeated or chronic illness was not associated with the children's developmental scores.

Special services and development outcome. The declines in developmental trajectories for these NICU graduates suggest that many should have been candidates for early intervention services. In the period from birth to 36 months, the numbers of children receiving any educational, therapeutic or NICU clinic service were: 23 out of the 31 children in the high-risk group, 11 of the 26 moderate-risk children, and 8 of the 30 low-risk children. Given these children's generally low developmental scores, the numbers receiving special services are remarkably low. Moreover, almost all children in services had received a specific medical diagnosis. Some parents discontinued services after several months either because of transportation and scheduling problems or because they felt the service was not helpful. In several cases, parents felt services were so limited that the child did not benefit enough to be worth the difficulties of getting the child to the service setting.

Thus, the overall service delivery picture for these at-risk children is one of missed opportunities and minimal intervention. It took a medical diagnosis to ensure service provision, and the service was often available infrequently and for only short sessions. For most children in this sample, developmental test scores showed significant delays in one or more areas, yet usually no professional had conducted an evaluation or recommended services to prevent further delay.

Implications for educational policy and practice

The FACT Study provides important information regarding likely developmental outcomes of children whose birth status places them at risk for delay or disability. The data demonstrate



extensive gaps in the service delivery system for infants and toddlers. Not all families have access to or information about services. Most of the children in this sample, despite their NICU stay and at-risk status, never had full evaluation of their developmental status.

Although Part H of IDEA recognizes that early intervention services should be available in all settings serving children and families, the NICU still focuses narrowly on medical treatment of infants and only up to about 18 months; families usually have to find educational and therapeutic services on their own. Moreover, Part H has emphasized coordination of existing services and elimination of duplicated services rather than addition of new or expanded services. The FACT Study results show that new and better services are needed in areas where early intervention services are limited. Families' individual needs must be considered; for the FACT Study families, getting a child to a service on an irregular basis at inconvenient times set by the agency often led to discontinuing services. Support is needed for Child Find and tracking systems to identify children and families at risk for developmental delays and disabilities as early as possible. Other needs are expansion of home- and classroom-based programs for educational stimulation and early intervention, and their availability in regular child-care settings.

<u>Prevention</u>. The results suggest that provision of a Family Services Coordinator to give families of NICU graduates support and information and help arrange for comprehensive early intervention services for the children would be useful. We would expect children who received preventive intervention services throughout their first three years not to show the same kinds of developmental declines typical of the present sample. We would also predict that specific diagnoses, often not made until age 3 or 4 in the present sample, would be made earlier, and specialized services could then prevent anticipated performance deficits.

Many families with preschoolers with special needs may not know that they qualify for federally-mandated services. It is frequently not until children reach kindergarten or early school that developmental delays, often preventable, are identified. The present findings strongly suggest that NICU admission should be considered an eligibility criterion for infant-toddler services. If all children in the NICU were included, so that IFSPs were developed and implemented for them early on, many more families of children who could benefit from preventive intervention would be encouraged to access such services.

Given the human cost of the developmental delays observed in the FACT Study and the financial cost of school special education services later, preventive early intervention services should be available to all children identified as at risk. Further studies to demonstrate the efficacy of preventive intervention across a range of risk/disability conditions and family situations will be crucial if resources are to be redirected toward prevention rather than treatment.

<u>Dissemination</u>. Papers describing the findings of this ongoing study and the implications for policy and practice are in preparation, for submission to national journals in the fields of child development, early education and early intervention. The work will continue to be presented at national, regional and local professional meetings.



TRAINING ACTIVITIES

The Institute's structure has offered graduate students an ideal opportunity for multi-disciplinary research and dissemination experiences in topics related to transitions of young children with disabilities and their families. Over the Institute's five years, a total of 63 predoctoral students were appointed as graduate trainees (15 to 24 trainees each year), in areas as diverse as allied health, human development and family life, medicine, psychology, sociology, special education, and speech-language-hearing. Trainees typically served on one of the KECRI research projects for at least a year, and often, in the case of doctoral students, for several years, for at least 10 hours a week. Trainees have worked with individual project investigators as mentors and helped design and implement specific studies. They also participated in other activities relevant to cross-disciplinary training in transition topics, as the opportunities arose.

In addition to the graduate trainees, a total of 34 undergraduate and graduate student research assistants performed a variety of specific duties as directed by project investigators. Research assistants' experience with the Institute was often an integral part of their degree—for example, as a practicum supplementing coursework, or in generating a required research paper.

For the formal graduate trainees, the Institute's training objectives were:

- ► TO PROVIDE INTENSIVE PRACTICAL RESEARCH EXPERIENCES AROUND A SPECIFIC SET OF RESEARCH QUESTIONS IN A TRAINEE'S AREA OF STUDY, COVERING SUCH ASPECTS AS METHODOLOGY, LITERATURE REVIEW, DESIGN OF STUDY, DATA COLLECTION, DATA ANALYSIS, INTERPRETATION OF RESULTS, WRITING AND PRESENTATION OF PAPERS;
- ► TO PROVIDE EXPOSURE TO THE RESEARCH OF ALL THE DISCIPLINES REPRESENTED IN THE INSTITUTE, INCLUDING THE DIFFERENT THEORETICAL FRAMEWORKS, RESEARCH MODELS, METHODS, AND PROCEDURES.

The first objective has been addressed at the level of individual trainee participation. The second objective was addressed at the level of group participation.

Trainees' specific research activities were assigned by the principal investigator of the KECRI project to which the trainee was attached. Trainees' responsibilities have included, for example, helping design research instruments, conducting interviews with parents of children with disabilities, carrying out comprehensive literature searches and reviews, helping analyze data, scripting, filming and editing instructional videotapes for families of children with special needs or professionals who work with them, producing instructional manuals for parents and professionals, writing research reports, giving conference presentations, and conducting their own training workshops and seminars.

As a group, trainees participated in the All-Institute meetings, Training meetings, and KECRI workshops and seminars with guest speakers. These meetings afforded valuable instructional occasions in exposing trainees to the ways of research and to disciplines outside their own area.

In addition to their activities with the Institute, trainees completed courses at the University of Kansas Lawrence and Medical Center campuses as needed to fulfill their degree requirements



and as advised by their project principal investigators. Trainees were encouraged to include courses from a variety of disciplines.

As of fall 1993, a total of 63 of the students affiliated with the Institute had already graduated with degrees from the University of Kansas, 51 at the Master's level degree, and 12 at the doctoral level. They are now employed across the nation in a large variety of positions, almost all in fields related to young children with disabilities and their families, for example, as clinical practitioners directly serving children and families, as regular or special educators or administrators in the field of early childhood education, or as teachers of trainees who themselves will go on to work with these populations.

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- Dr. Marion O'Brien, Co-Director
- Dr. Judith E. Thiele, Asst. Director (10/90 to 9/92)
- Dr. Carolyn Roy, Asst. Director and Dissemination Coordinator

PROJECT INVESTIGATORS

- Project 1.1: Parental Adjustment to the birth of a child with disabilities and early hospital transitions: An audiovisual parent-to-parent informational model.
 - PI: Daryl Evans, Ph.D., Sociology Department, KU
- Project 1.2: Planning transition from the Neonatal Intensive Care Unit to the home.
 - Pls: Nancy E. Meck, Ph.D., Child Development Unit (CDU), KU Medical Center
 - Susan Fowler, Ph.D. (formerly with Life Span Institute, KU)
 - Joseph G. Hollowell, M.D., (formerly with CDU, KU Medical Center)
 - Katherine Claflin, M.D. (formerly with Pediatrics Dept.,
 - KU Medical Center)
- Project 1.3: In-home intervention to facilitate the transition from NICU-to-home.
 - Pls: Kathleen McCluskey-Fawcett, Ph.D., Psychology Department, KU Marion O'Brien, Ph.D., Human Development & Family Life, KU
- Project 2.1: Programming a successful transition from home to preschool: Developing individualized treatment programs to teach appropriate social skills.
 - Pls: Susan A. Fowler, Ph.D., formerly with Life Span Institute, KU Alita Cooper, M.A., Human Development & Family Life, KU
- Project 2.2: Transitioning preschool children with severe and profound multiple disabilities from a special education classroom program into mainstream Montessori preschool and child care programs.
 - PIs: Barbara Thompson, Ph.D., Special Education Department, KU Jane Wegner, Ph.D., Speech-Language-Hearing Department, KU



Project 2.3: Verbal interactive skills training for transitions.

Pls: Mabel L. Rice, Ph.D., Speech-Language-Hearing Department, KU Kim A. Wilcox, Ph.D., Speech-Language-Hearing Department, KU

Project 2.4: Transfer of information on Child Academic Skills and classroom procedures from Preschool to

parents, and parents to preschool, as a pretransition intervention for successful school entry.

PIs: Barbara C. Etzel, Ph.D., Human Development & Family Life, KU Judith M. Leblanc, Ph.D., Human Development & Family Life, KU

Project 3.1: Programming successful classroom transition: Assessment of children's survival skills and

classroom requirements.

PIs: Judith Carta, Ph.D., Juniper Gardens Children's Project, KU
Jane B. Atwater, Ph.D., Juniper Gardens Children's Project, KU
Charles R. Greenwood, Ph.D., Juniper Gardens Children's Project, KU

Project 3.2: Promoting successful transition to the primary grades: Prediction of reading problems in children

with speech and language disabilities.

PI: Hugh W. Catts, Ph.D., Speech-Language-Hearing Department, KU

Project 4.1: Assessing concerns of families in transition and promoting family directed problem-solving.

PIs: Yolanda Suarez, Ph.D., formerly with Life Span Institute, KU Stephen B. Fawcett, Ph.D., Human Development & Family Life, KU

Project 4.2: Role of professionals in successful transitions.

PI: Winnie Dunn, Ph.D., Occupational Therapy Education, KU Medical Center

Project 5.0: The longitudinal study of families and children in transition.

PIs: Marion O'Brien, Ph.D., Human Development & Family Life, KU

Mabel L. Rice, Ph.D., Speech-Language-Hearing, KU

Judith E. Thiele, Ph.D., formerly with Child Development Unit,

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